

Coalition Priorité Cancer and the Pharmaceutical Industry in Quebec: Conflicts of Interest in the Reimbursement of Expensive Cancer Drugs?

Coalition Priorité Cancer et industrie pharmaceutique au Québec : conflits d'intérêts dans le remboursement des médicaments anticancéreux coûteux?



DAVID HUGHES, MA

*Doctoral Student, Applied Human Sciences (Bioethics Option)
Bioethics Programme, Department of Social and Preventive Medicine
University of Montreal
Montreal, QC*

BRYN WILLIAMS-JONES, PHD

*Associate Professor and Director, Bioethics Programme,
Department of Social and Preventive Medicine
University of Montreal
Montreal, QC*

Abstract

In the context of scarce public resources, patient interest groups have increasingly turned to private organizations for financing, including the pharmaceutical industry. This practice puts advocacy groups in a situation of potential conflicts between the interests of patients and those of the drug companies. The interests of patients and industry can converge on issues related to the approval and reimbursement of medications. But even on this issue, interests do not always align perfectly.

Using the Quebec example of Coalition Priorité Cancer (CPC) as a case study, we examine the ethical issues raised by such financial relationships in the context of drug reimbursement decision-making. We collected, compiled and analyzed publicly available infor-

mation on the CPC's organization and activities; this approach allowed us to raise and discuss important questions regarding the possible influence exerted on patient groups by donors. We conclude with some recommendations.

Résumé

Dans le contexte où les ressources publiques sont limitées, les groupes de défense des intérêts des patients se tournent de plus en plus vers les organismes privés, dont l'industrie pharmaceutique, pour obtenir du financement. Cette pratique met ces groupes dans une situation potentielle de conflit entre les intérêts des patients et ceux des sociétés pharmaceutiques. Les intérêts des patients et ceux de l'industrie peuvent converger sur les enjeux liés à l'approbation et aux remboursements des médicaments. Mais même dans ce cas, les intérêts respectifs ne s'harmonisent pas toujours parfaitement.

Avec l'exemple québécois de la Coalition Priorité Cancer (CPC) comme étude de cas, nous examinons les enjeux éthiques soulevés par une telle relation de financement dans le contexte des décisions touchant au remboursement des médicaments. Nous avons recueilli et analysé des renseignements accessibles au public sur l'organisation et les activités de la CPC; cette démarche nous a permis de soulever et de discuter d'importantes questions au sujet d'une possible influence exercée par les donateurs sur les groupes de patients. En guise de conclusion, nous formulons quelques recommandations.

IN OCTOBER 2011, THE NATIONAL INSTITUTE FOR EXCELLENCE IN HEALTH AND SOCIAL Services of Quebec (INESSS) announced that for cost-effectiveness reasons, it could not recommend to the Ministry of Health the reimbursement of four cancer drugs that were under evaluation: Iressa, Tarceva and Alimta for lung cancer, and Afinitor for kidney cancer. This decision was immediately denounced by Coalition Priorité Cancer (CPC) – a Quebec-based patient advocacy group (Lacoursière 2011a). The CPC critique was taken up in the Quebec National Assembly by the then official opposition, the Parti Québécois, further increasing pressure on the Liberal Minister of Health at the time, Dr. Yves Bolduc. The Minister intervened with INESSS and, in November 2011, announced the reimbursement of three of the four drugs that had initially been rejected (Iressa, Tarceva and Alimta) (Krol 2011). Following this shift, an article published in the French-language newspaper, *Le Devoir*, raised questions about the possible influence that the pharmaceutical industry had on the CPC (Daoust-Boisvert 2011) and, by extension, on government decision-making. Specifically, the article pointed out that the manufacturers of the drugs in question – AstraZeneca, Eli Lilly, Hoffman-LaRoche and Novartis – had each provided significant financial support to the CPC, bringing into question the interest group's independence and the potential for indirect influence of the pharmaceutical industry on government decisions. This story was then picked up by various media, to which the CPC responded by reaffirming its independence (Lacoursière 2011b).

Pharmaceutical industry funding of patient or disease interest groups raises important ethical issues related to conflicts of interest (COIs) and public trust. Of particular concern is the “subversion” or “co-opting” of patient interest groups to advance industry agendas. Using the Quebec example of CPC as a case study, we will examine the ethical challenges – and in particular, the financial COIs – faced by patient interest groups, in order to reflect on the responsibilities of both these groups and industry with regard to the very problematic COIs that arise when the latter contribute to financing the activities of the former.

Background

Patient interest or advocacy groups commonly provide their members (i.e., patients and their families) with accessible information about their condition (e.g., aetiology, possible treatments) and support to live with the condition. Some of these groups also try to encourage research on their specific condition by engaging in public fundraising campaigns and calling upon policy makers to create more favourable conditions for the conduct of research and the development of treatments. These groups can also represent their patient-members in the media and before government, appearing before or even participating as members of regulatory agencies and health policy or public advisory committees (e.g., patient interest groups are represented on the Australian Pharmaceutical Benefits Advisory Committee and on committees of the UK evaluation agency, the National Institute for Health and Care Excellence [NICE]) (Allsop et al. 2004; Lofgren 2004).

Patient interest groups are largely volunteer run and often function with very limited operating funds, much of which come from private donations but also from government grants. In the last few decades, however, governments in many developing countries have significantly reduced funding to citizen groups of all sorts. In Canada, since the 1990s, a context of fiscal restraint and a changing public role of citizen groups has led to a substantial reduction in the funding of interest groups by the federal government (Jensen and Phillips 1996). As such, patient groups have increasingly chosen to turn to private organizations, including the pharmaceutical industry, to find funding for their various activities. A study by Ball and colleagues (2006) of patient interest groups in the United States, the United Kingdom, Australia, Canada and South Africa found that of 69 groups studied, 45% declared industry funding on their group websites. Similarly, Hemminki and colleagues (2010) found that 71% of groups in Finland were funded by drug manufacturers, while O'Donovan (2007) noted industry support in at least 47% of groups in Ireland.

From the perspective of the pharmaceutical industry, an association with patient interest groups has many advantages. Such collaborations enable interest groups, and thus patients, both to access and to share information regarding manufacturer products that are directly related to their conditions. In addition, because interest groups put a human face on disease, they add credibility to causes that the industry advocates (Hemminki et al. 2010; Lofgren 2004). But relations between patient interest groups and the pharmaceutical industry are extremely varied, and can be characterized by refusing funding on the one hand, and cooperation or even co-optation on the other.

1. Refusing industry funding: Some groups refuse any funding from industry, motivated by political reasons or the desire to maintain their independence and public credibility. For example, Breast Cancer Action of San Francisco explicitly refuses industry funding to safeguard its credibility and political legitimacy (Batt 2005; O'Donovan 2007). Breast Cancer Action Montreal and the Society for Diabetic Rights are examples of this type of group in Canada. Some health consumer groups, such as Women and Health Protection, PharmaWatch and the Canadian Health Coalition, also operate completely independently of industry funding.¹
2. Cooperation: Groups that agree to accept some industry funding may be more or less cautious in their relations. They may require different degrees of disclosure in their annual reports or on their websites (simply the names of donors, full disclosure of amounts received, program funded or percentage of total budget). In cases of project funding and activity sponsorship, Canadian Cancer Action Network's policy stipulates that "the sponsor will be acknowledged in a way that is agreed in negotiations with the company." Unlike most groups, Epilepsy Action Australia specifies the amounts of donations from drug companies in its annual report (Ball et al. 2006). Some groups may also require "no strings attached" agreements for any funding in order to maintain their independence. For example, Fibromyalgia and Chronic Fatigue Syndrome Canada's policy requires a written agreement "recognizing the autonomy and independence of FM-CFS Canada and its activities separate from any influence of the supporting company." It also requires that all educational grants be unrestricted (FM-CFS Canada 2004). However, the Canadian Cancer Action Network's policy, while maintaining its groups' editorial control over all material, allows companies that fund specific projects to have representation on its steering committee (CCAN 2012). Other groups may be much less concerned with the problems that can result from such partnerships and not have formal guidelines or procedures.
3. Co-optation: There are some cases where organizations have been completely co-opted by industry (e.g., Society for Women's Health Research in the United States; see Mundy 2003) or even created from scratch by the industry while still giving the appearance of being independent grassroots organizations (Herxheimer 2003; O'Donovan 2007). Yet, if these groups become seen as representing the interests of industry, they then run the risk of losing their public credibility and utility for industry (Herxheimer 2003; Jacobson 2005; Rothman et al. 2011).

The interests of patients and industry can converge on issues related to the approval and reimbursement of medications (Hemminki 2010; Jones 2008). Patients and interest groups legitimately desire access to better and more effective medicines, while the industry is interested in expanding its market share or getting a new medication reimbursed by health insurers. When such interests align, it may be very advantageous for manufacturers to finance

the activities of patient interest groups.

In lobbying governments and intervening in the media, patient groups can be very effective at advancing certain agendas. These groups can influence the decisions of evaluation agencies (and have done so in the past) in favour of certain medications, or even contribute to overturning decisions regarding inclusion in drug insurance plans (Ferner and McDowell 2006). For example, the UK Alzheimer's Society's campaign against a NICE decision contributed to widened access to Aricept, Exelon, Reminyl and Ebixa (Alzheimer's Society 2011). In addition, Carpenter (2004) has shown that the time required for the US Food and Drug Administration (FDA) to review and approve a drug was shorter when the medical condition in question was represented by advocacy groups that were well organized and funded. However, this type of relationship can lead to important pitfalls. For example, a study among European patient and consumer organizations has revealed an association between receiving drug company funding and supporting an expanded role for these companies as information providers (Perehudoff and Alves 2011). Potential problems are even explicitly recognized by Canada's Research-Based Pharmaceutical Companies, the association that represents the pharmaceutical industry: "Given the range of issues in common, it is natural that the pharmaceutical industry and stakeholder groups should work together. However, the industry also recognizes that there exists the potential for conflict of interest, either real or perceived, in the relationship" (Rx&D 2009a).

In this paper, we focus on the case of Coalition Priorité Cancer (CPC), a Quebec-based patient interest group that is very active on issues of oncological drug reimbursement. While likely an outlier among the diverse patient interest groups in Quebec in terms of its industry funding (which is substantial), its influence with provincial decision-makers makes it an important actor to study, and a notable example of the challenges both for patient groups and for the pharmaceutical industry in managing potentially very problematic COIs.

Methods

For this study, we followed three general steps. First, we conducted a broad, non-systematic literature review on the relationship between patient groups and drug companies to identify key analytical elements and main problems related to such relationships. Second, we collected all the information publicly available on the history and activities of CPC (Appendix 1 available online at longwoods.com/content/23466) from its creation in 2001 to the end of 2011, as well as a list of its members (Appendix 2 available online at longwoods.com/content/23466). Information sources on the CPC included:

1. the CPC website (<http://www.coalitioncancer.com>);
2. newspaper stories (*La Presse*, *Le Devoir*);
3. comments in the Quebec National Assembly (<http://www.assnat.qc.ca>);
4. publicly available documents related to forums, symposia and conferences organized by the CPC (event programs, presentations, etc.);

5. two special sections (“cahiers spéciaux”) published by the CPC in the newspaper *Le Soleil* (2009 and 2011); and
6. studies, polls and petitions ordered by the CPC.

Most of the information was obtained directly from the CPC website, but also by searching Google and the Quebec National Assembly’s website for the keywords “Coalition Priorité Cancer.” To select newspaper articles, we searched the Eureka database (www.biblio.eureka.ca) for the keywords “Coalition Priorité Cancer” to identify relevant articles in the French-language press in Quebec. (French in-text citations are translated into English, and newspaper stories are referenced: D = *Le Devoir* and P = *La Presse*, followed by date of publication). Third, CPC’s organization, activities and interventions were analyzed deductively, based on the elements identified in the literature review. The content of newspapers was not inductively and independently analyzed. It was used just as were other sources of information on CPC. All three appendices were compiled by the authors. The information on evaluation status of drugs in Appendix 3 (available online at longwoods.com/content/23466) was obtained from the INESSS evaluation reports available on that agency’s website (www.inesss.qc.ca).

Results and Discussion

The main analytical elements and potential issues that were identified in the literature were:

1. the portion of a patient interest group’s income that comes from industry;
2. the fact that manufacturers tend to support groups working in their particular therapeutic areas – this provides a clue to the interested nature of their donations;
3. the influence of donors on the orientation of groups through funding certain activities rather than others;
4. the tendency of patient interest groups that receive industry funding to defend the industry’s position that the drug assessment and approval process is too long and too strict – a position that focuses on access and may downplay other criteria, such as safety and efficient use of resources;
5. neglect by patient groups of questions about drug pricing and drug price policies; and
6. conflict of interest management and disclosure practices.

In the following discussion, we develop each point and explore points in relation to the case of CPC and to interest groups in general.

The CPC brings together 40 organizations (e.g., interest groups, professional organizations, university research chairs), and was established in 2001 to “defend and give a voice to those affected by cancer (patients, survivors, their families and their relatives) and to strengthen the organization of the fight against cancer” (CPC 2012a). The group’s main declared objectives are:

- to develop – in partnership with various actors in the fight against cancer, including civil society leaders and political decision-makers – a provincial plan to fight cancer;

- ♦ to promote the creation of an agency to better coordinate and strengthen the fight against cancer;
- ♦ to propose and support any measure that improves services to all people affected by cancer;
- ♦ to develop partnerships between community organizations, the healthcare system and government;
- ♦ to ensure a continuous surveillance of the fight against cancer; and
- ♦ to educate, raise awareness and mobilize the public (CPC 2012a).

The CPC's activities include the production of surveys, petitions, forums, conferences, press conferences and press releases (Appendix 1). It is funded by contributions from member organizations (Appendix 2) on an annual basis or for a specific activity, individual registrations in the various CPC activities, and financial assistance from the public and private sectors, including 13 drug manufacturers (Appendix 3).

The portion of a patient interest group's operating funds that comes from industry, as compared with individual donations or government support, is a key issue raised in the literature. In some cases, the percentage of operating funds from industry may be relatively limited, such as 6% to 7% for the Canadian Arthritis Society or 9% in the case of Cancerbackup (Mintzes 2007). But industry funding may be more substantial in some cases, reaching 30% for the Diabetes Federation of Ireland (O'Donovan 2007). In their study of 39 Finnish organizations that reported receiving funding from industry, Hemminki and colleagues (2010) noted that for four groups, this funding represented more than 20% of their annual budgets. In the case of the CPC, 60% to 65% of its budget came from the pharmaceutical industry in 2011 (Daoust-Boisvert 2011), a figure that is extremely high when compared to other cases cited in the literature. Although the relative portion of an operating budget is one indicator of the importance of the financial COI, the absolute value of funding is also meaningful, as even a small percentage of a very large budget may represent a considerable amount of money.

A study by Rothman and colleagues (2011) suggests that manufacturers tend to support groups working in their particular therapeutic areas. This implies, not surprisingly, that the industry's support of patient interest groups is not purely altruistic, but interested. Of the 13 pharmaceutical companies financially supporting the CPC in 2011–2012, all have an interest in oncology. Moreover, in 2011–2012, the 13 manufacturers all had products either rejected in evaluation or not yet evaluated (Appendix 3). All these companies had a clear interest in seeing the CPC support their cases before decision-makers and regulators, especially concerning the approval and reimbursement of their drugs.

In the absence of "no strings attached" agreements, donors may have some influence on the orientation of groups by funding some activities rather than others. It should be noted that most CPC activities known to be specifically funded by drug companies deal with the issue of reimbursement of cancer drugs (conferences in 2010 and 2011; "cahiers spéciaux" in 2009 and 2011). From 2009 onwards, the issue of drug reimbursement assumed greater prominence in the CPC's activities, and in 2011 it became predominant.

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Evaluation agencies such as INESSS in Quebec have the responsibility to make recommendations regarding the approval and reimbursement of pharmaceutical drugs based on their safety, effectiveness and efficiency (cost–benefit), and the fairness and sustainability of the drug offer. Batt (2009) noted that Canadian health interest groups receiving industry funding (e.g., Best Medicine Coalition) tend to defend the industry’s position that the drug assessment and approval process is too long and too strict. Conversely, those groups receiving no funding from industry (consumer groups such as Women and Health Protection, PharmaWatch and the Canadian Health Coalition) tend to advocate for greater drug regulation and safety standards, both before and after marketing. While patient interest groups are heterogeneous in their constitution, membership, mission and functioning, such a dichotomy between those groups that receive and those that do not receive industry funding can lead one to hypothesize that significant financial interests could have an important impact on or even shape the behaviour of these groups. The CPC fits the pattern because it has taken the industry’s position on numerous occasions: e.g., “The Coalition therefore urges Québec to review the functioning of the Conseil [du médicament] that it considers too slow and too severe” (D.2010.12.09).

However, accelerating and easing the evaluation process is often associated with less evidence and more risk to patients (Abraham and Davis 2002). In this respect, the position of the CPC on Avastin, for metastatic breast cancer, appears problematic. Avastin was approved for this indication by the FDA in 2008 and by Health Canada in 2009, but these approvals were conditional on obtaining additional data, as efficacy and safety had not been clearly established. In June 2011, with no study having yet demonstrated the effectiveness and safety of Avastin for breast cancer, a study committee of the FDA recommended revoking the approval of the drug for this indication (Mai-Duc 2011); in November, the FDA and Health Canada followed this recommendation (Pollack 2011). Yet, in October, although the FDA had already recommended the withdrawal of Avastin, the CPC denounced INESSS’s rejection of eight cancer drugs for metastatic breast cancer, including Avastin (CPC press release 2011.10.04; Derfel 2011). In its interventions, the CPC never mentioned the questions raised by the FDA study committee surrounding Avastin’s safety and effectiveness for treating breast cancer.

The CPC’s opinion on the unreasonable severity of the drug evaluation process not only concerned the criterion of therapeutic value, but also the criterion of efficiency (cost–benefit ratio): “The process of approval of these drugs is very long and, in cases of refusal, financial arguments take too much space, also deplores Dr. Audet-Lapointe” (P.2010.12.09). From our analysis and based on the information we collected, the evaluation criterion of efficiency does not appear to be relevant for the CPC. In fact, it often asks: “What is the cost of life in Quebec?” (CPC press release, 2011.10.04; P.2011.10.05). The underlying idea seems to be that life has no price. However, drug reimbursement without regard to costs is not a responsible and efficient use of resources and can threaten the sustainability of drug insurance plans (Ferner and McDowell 2006). In addition, any inclusion of a new drug has an opportunity cost, that is to say, it necessarily implies the abandonment of or reduction in access to another

service (Drummond et al. 2005). It is thus important to consider whether the reimbursement of these expensive, low-efficiency drugs constitutes the best use of resources in the fight against cancer (Hughes 2012).

Besides putting pressure on agencies and policy makers to approve and pay for certain drugs, patient interest groups could also put pressure on industry and governments to lower drug prices. However, as noted by Batt (2005), “drug pricing in itself has been a neglected area for direct lobbying by patient and health advocacy groups in Canada” (p. 12). This choice of target is probably not unrelated to the fact that many interest groups receive industry funding. But it might also be due to the fact that these groups have been less able to leverage the scientific (health economics) expertise necessary to push for reduced pricing. When the challenge was simply gaining access to needed medications for their members (i.e., reimbursement on drug plans), the actual cost of the drug was a secondary or subsidiary consideration.

While the CPC is constantly urging the INESSS and health insurers to make concessions on the price of anticancer drugs, we found no evidence that it similarly calls on manufacturers to reduce those prices (Gagnon 2012). Nor did we find any evidence of the CPC’s denouncing the failure by the pharmaceutical industry to respect agreements with the Government of Quebec to ensure the lowest price paid in Canada (BAP rule: Best Available Price). Indeed, manufacturers concluded secret agreements with other provinces on the price of anticancer drugs, agreements that contravene the Quebec BAP rule (Gagnon 2011).

A first step towards better management of conflict of interest is transparency and disclosure (Hurst and Mauron 2008). The Association of the British Pharmaceutical Industry (ABPI) and the European Federation of Pharmaceutical Industries and Associations (EFPIA) have codes of practice that require member companies to make public a list of organizations to which they provide support. The list must include the amount of financial assistance and a detailed description of non-financial support (ABPI 2012; EFPIA 2011). In Canada, the Rx&D’s “Guidelines for Transparency in Stakeholder Funding” recommend to members the disclosure, by means of their websites and annual reports, of all stakeholders to which they provide direct funding; but they do not require disclosure of the value of the support. The Rx&D code is voluntary, but membership in the organization requires companies to abide by the code (Rx&D 2009b). There is no equivalent to the ABPI or EFPIA for patient interest groups that sets standards of practice or offers guidelines for this community.

A UK study found that only 26% of the 246 patient advocacy groups receiving funding from the industry declare such information on their website: 22 groups name companies, 18 provide information on the type of activity funded, 14 on the amounts and 4 on the portion of their budget coming from industry (Jones 2008). Ball and colleagues (2006) analyzed 69 websites of national and international patient organizations based in the United States, the United Kingdom, Australia, Canada and South Africa, and found that only one-third specified the source of their funding and the donor’s name, but without necessarily specifying the amount of funding. Similarly, Rothman and colleagues (2011) found that among 161 US groups receiving funding from Eli Lilly, 25% reported receiving funding from this manufac-

turer and 10% stated the use of funds, but none disclosed the amounts received.

On the disclosure of funding sources, the practices of CPC are minimal. On its website, the group provides a list of pharmaceutical industry donors but without specifying the amounts or the use of donations; nor does the CPC provide a public annual report. However, for some specific activities, donors' logos appear on official documents ("états généraux," national conferences; "cahiers spéciaux"). The CPC website states that "[f]inancial contributions of our partners, whether from public institutions or private companies, are governed by a Policy on Partnerships from the Board of Directors of the Coalition and prevents any interference in the Coalition's governance" (CPC 2012b). And as quoted in an article in *Le Devoir*, according to the spokesman for the CPC, "[t]he Coalition does not depend on pharmaceutical companies in its decision-making" (D.2011.12.03). But no details concerning the Policy on Partnerships are given, nor is the policy available online. This omission clearly raises important questions. Even if industry donors are not directly involved in a group's decision-making processes – especially if the percentage of operating funds that come from industry is substantial – one can reasonably question whether the group is actually able to make decisions or take positions that go against the interests of their major donors.

Conclusion

Patient interest or advocacy groups play a significant role in raising awareness about specific illnesses, in supporting patients and in contributing to decision-making about the development and financing of new and existing drugs. In order to play this role effectively, these groups need financial support. In the context of scarce public resources, these groups have increasingly turned to the private sector for financing. With 60% of its funding coming from the pharmaceutical industry, the CPC is an example of a group that is particularly vulnerable to influence.

The interests of patients and industry can converge on issues related to the approval and reimbursement of medications. But even on issues of drug reimbursement, these interests do not always align perfectly. From our analysis and based on the available information, the CPC's commitment to its patient-members does not appear to be optimal on a number of different occasions. For example, the absence of a clear position or warning against Avastin for breast cancer raises some serious questions about the agency's role as a watchdog or source of reliable advice to its patient community. Moreover, the CPC's focus on the issue of reimbursement of expensive, low-efficiency drugs also raises questions, because such reimbursement has an important opportunity cost and does not appear to be the best way to use scarce resources to fight cancer. Finally, we found no evidence that the CPC has called for manufacturers to reduce prices, or lobbied the Quebec government to negotiate for lower drug prices, as do other provinces. Similarly, we found no evidence that the CPC has denounced the failure by the industry to respect agreements with the Quebec government in ensuring the lowest price paid in Canada.

In order for patient interest groups to manage the problematic financial COI in which they find themselves when they take funding from the private sector (e.g., pharmaceutical or

medical device industries), these groups should be, at a minimum, required to disclose donors' names publicly, as well as the amount, the nature and the use of the support they receive from public or private donors. They should also include details of COI of any advisers to the group, and disclosure material needs to be prominent and accessible. Furthermore, general donation should be preferred, and specific funding of activities discouraged, in order to limit the capacity of donors to subtly orient the groups' activities. Above all, more public funding would make advocacy groups less dependent on private industry sources. But in the current economic context of reduced public funding to patient interest groups, and given the evident difficulty in funding activities through individual private donations, many groups will choose to turn to the private sector for support. It then becomes essential that patient interest groups aim at full transparency regarding their fundraising activities, their operating budgets and their governance policies if they are to protect the trust that they have developed with their members and civil society. Such transparency would enable appropriate public scrutiny on the functioning of interest groups, making them less effective vectors of industry messages and thus less open to and less interesting for manipulation. Finally, an increased role for advocacy groups without industry funding may help to make debate about drug reimbursement and eventual policy decisions more credible and accountable.

Limitations

This study has several limitations. First, the information on CPC is limited to what was publicly available on the Internet and in the newspapers. For example, a spokesperson of the group mentioned that its relations with donors are regulated by a Policy of Partnership, but we did not contact CPC to obtain this document and so did not include it in our analysis. This approach reflects our normative stance that such information should be public and easily accessible if a group is to be both transparent and thus accountable. Second, our study did not allow us to make causal inferences, although we could nonetheless draw reasonable conclusions from the associations between company sponsorship and group positions and actions. Finally, while a case study does not allow any generalization to the practice of other patient groups, it does point to important issues of concern that are generalizable.

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Correspondence may be directed to: David Hughes, Bioethics Programme, Department of Social and Preventive Medicine, University of Montreal, C.P. 6128, succ. Centre-ville, Montreal, QC H3C 3J7; e-mail: david.hughes@umontreal.ca.

NOTE

1. Because the mission of most consumer groups is to protect consumers from corporate abuse (e.g., misleading advertising), they are much less likely than other advocacy groups (e.g., patient groups) to accept funding from drug companies.

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Appendix 1

Coalition Priorité Cancer Activities

Date	Activities	Themes
2001.05	Creation of the CPC in response to shortcomings of the 1998 <i>Programme de lutte contre le cancer</i> (P2001.05.07)	Healthcare organization; healthcare funding; human resources in oncology
2002.12	Document presented to the MSSS	Healthcare organization; human resources in oncology; patient support; cancer registry
2002.06	Filing of a petition of 42,000 names to the Quebec National Assembly	Access to healthcare; waiting time; healthcare funding
2003.02	Intervention in the media to denounce lack of organization in the fight against cancer (P2003.02.26)	Healthcare organization; healthcare funding; waiting time
2003.10	Document presented at the Deschênes committee (<i>Avis de la coalition priorité cancer au Québec présenté au docteur Luc Deschênes, président du groupe de travail ministériel</i>)	Healthcare organization; cancer registry; access to healthcare; waiting time; human resources in oncology; patient support
2004.04	Forum 2004: <i>Les Besoins des personnes touchées par le cancer</i> Publicized sponsors: FQC, SCC, Leucan, MSSS, etc.	Healthcare organization; access to healthcare; patient support; prevention
2005	Forum 2005: <i>Le Rôle des acteurs, réalités des intervenants et pratiques exemplaires</i> Publicized sponsors: No public document found	No public document found
2005.04	Intervention in the media to denounce lack of organization in the fight against cancer (P2005.04.17)	Healthcare organization; waiting time; human resources in oncology; access to healthcare
2006	Forum 2006: <i>Les Enjeux socio-économiques reliés au cancer</i> Publicized sponsors: No public document found	No public document found
2006.04	Intervention at the parliamentary commission on the project <i>Garantir l'accès</i> (D.2006.04.13)	Healthcare organization; waiting time; cancer registry
2006.12	Intervention in the media – communiqué to denounce the government's decision not to subscribe to the Canadian Partnership Against Cancer (D.2006.12.14)	Healthcare organization; waiting time; cancer registry; screening
2007.03	Intervention in the media – press conference in the context of provincial elections (D.2007.03.12; P2007.03.13)	Healthcare organization; research; prevention; screening; waiting time; cancer registry
2007.09	Intervention in the media – press conference in response to the new orientations of the <i>Programme québécois de lutte contre le cancer</i> (D.2007.09.26)	Healthcare organization; cancer registry; patient support
2007.09	États généraux de la lutte contre le cancer – report presenting 68 propositions (2007.11)	Healthcare organization; cancer registry; research; prevention; screening; access to healthcare; patient support; drug reimbursement
2008.04	Intervention in the media – press conference in the context of the publication of the Canadian Cancer Society statistics (P2008.04.14; D.2008.04.14)	Healthcare organization; cancer registry; research; prevention; screening
2009.05	CPC's survey on healthcare access in oncology (P2009.05.09; D.2009.05.09) Publicized sponsors: Réseau d'action de lutte au cancer	Access to healthcare; patient support; cancer registry
2009.05	Conférence nationale 2009 pour vaincre le cancer (program) Publicized sponsors: Astra, GSK, Merck, Pfizer, Roche, Sanofi, MSSS, etc.	Prevention; screening; patient support; research
2009.06	Cahier spécial 1 published in <i>Le Soleil</i> newspaper (2009.06.14) Publicized sponsors: Astra, Novartis, Sanofi, Pfizer, Rx&D, FQC, SCC, etc.	Access to healthcare; prevention; drug reimbursement; research; patient support
2009.06	Intervention in the media – interview: CPC asks the government to order new breast cancer tests and to submit all laboratories to quality control (P2009.06.01; D.2009.06.01; P2009.06.03)	Diagnosis; healthcare organization
2009.06	Intervention in the media – communiqué: Medical isotopes – CPC deplores the fact that Ottawa did not take action when the reactor broke down in 2007 (P2009.06.11)	Shortage of medical isotopes
2009.07	Intervention in the media – interview: CPC invites the public to write to the Prime Minister of Canada to denounce the inaction of the federal government (P2009.07.31)	Shortage of medical isotopes
2009.12	Intervention in the media – interview: CPC asks government to use higher standards while checking breast cancer tests for errors (P2009.12.17; P2009.12.18; D.2009.12.18)	Diagnosis; healthcare organization
2010.02	CPC invites the public to sign a petition asking the provincial government to create an oncology agency (P2010.02.05; D.2010.02.05)	Healthcare organization
2010.04	CPC study on the costs of cancer (<i>study report</i>) Publicized sponsors: MSSS	Patient support; cancer registry
2010.04	Conférence nationale 2010 pour vaincre le cancer (<i>program</i>) Publicized sponsors: Astra, BMS, Merck, GSK, Novartis, Pfizer, Roche, Sanofi, MSSS, Desjardins	Access to healthcare; drug reimbursement; research; patient support; screening; healthcare organization; human resources in oncology
2010.05	Intervention in the media – press conference in response to the publication of the Canadian Cancer Society's statistics (P2010.05.21; D.2010.05.21)	Cancer registry; screening; access to healthcare; healthcare organization
2010.09	Intervention in the media in response to the publication of Statistics Canada's findings (D.2010.09.17)	Cancer registry; healthcare organization; access to healthcare
2010.12	Intervention in the media in response to INESSS's decision not to recommend cancer drugs (P2010.12.09; D.2010.12.09)	Drug reimbursement
2011.03	Regional tour in 8 cities in Quebec (D.2011.03.28)	Access to healthcare; waiting time; healthcare organization; cancer registry; drug reimbursement
2011.04	Intervention in the media – interview in response to the creation of the Quebec cancer registry (D.2011.04.12)	Cancer registry
2011.04	Conférence nationale 2011 pour vaincre le cancer Publicized sponsors: Amgen, Astra, Boehringer, BMS, GSK, Lilly, Merck, Novartis, Pfizer, Roche, Sanofi, Janssen, Desjardins, Gesca, etc.	Healthcare organization; research; prevention; screening; drug reimbursement; patient support
2011.05	CPC survey on access to cancer healthcare (P2011.05.18)	Access to healthcare; drug reimbursement
2011.05	Cahier spécial 2 published in newspaper <i>Le Soleil</i> (2011.05.05) Publicized sponsors: Eli Lilly, Merck, Novartis, Amgen, GSK, FCC	Healthcare organization; access to healthcare; drug reimbursement; patient support; research
2011.10	Intervention in the media – press conference in response to INESSS's decision not to recommend cancer drugs (P2011.10.04; P2011.10.05; D.2011.10.05)	Drug reimbursement
2011.11	Symposium sur l'accès aux médicaments et aux traitements de pointe en cancer Publicized sponsors: No public document found <i>Le Devoir</i> raises questions about CPC's funding by the pharmaceutical industry (D.2011.11.28). CPC denies being influenced by its sponsors (P2011.11.29).	Drug reimbursement

Acronyms: BMS=Bristol-Myers Squibb; CPC=Coalition priorité cancer; FQC=Fondation québécoise du cancer; GSK=GlaxoSmithKline; INESSS=Institut national d'excellence en santé et en services sociaux; MSSS=Ministère de la santé et des services sociaux du Québec; Rx&D=Canada's Research-Based Pharmaceutical Companies; SCC=Société canadienne du cancer

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Appendix 2

Members of Coalition Priorité Cancer

ACCC: Association canadienne du cancer colorectal
ACCÉSSS: Alliance des communautés culturelles pour l'égalité dans la santé et les services sociaux
ACEQ: Association du cancer de l'est du Québec
Administrateur Coalition priorité cancer au Québec
APQ: Association pulmonaire du Québec
APTS: Alliance du personnel professionnel et technique de la santé et des services sociaux
AQL: Association québécoise du lymphoedème
AQRO: Association québécoise des registraires en oncologie
AREQ (CSQ): Association des retraités et retraitées de l'éducation et des autres services publics
AROQ: Association des radio-oncologues du Québec
Association des laryngectomisés de Montréal
Chaire en prévention et traitement du cancer de l'UQAM
Chaire Environnement-Cancer Guzzo de l'Université de Montréal
COC: Cancer de l'ovaire Canada
Corporation de sensibilisation VPH
Fondation des étoiles
Fondation lymphome Canada
FQC: Fondation québécoise du cancer
FQM: Fédération québécoise des massothérapeutes
FQM: Fondation québécoise de la massothérapie
FTQ: Fédération des travailleurs et travailleuses du Québec
Institut de l'anémie – Recherche en éducation (IARE)
L'Espoir, c'est la vie
Mains de l'espoir de Charlevoix
Myélome Canada
Nova Montréal
OGPAC: Organisme gaspésien des personnes atteintes de cancer
OMPAC: Organisation multiressources pour les personnes atteintes de cancer
OPTMQ: Ordre professionnel des technologistes médicaux du Québec
OQPAC: Organisation québécoise des personnes atteintes de cancer
OTIMRO: Ordre des technologues en imagerie médicale et en radio-oncologie du Québec
Ovaire espoir
Procure: Halte au cancer de la prostate
Q-CROC: Consortium de recherche en oncologie clinique du Québec
RCCS: Réseau canadien du cancer du sein
Réseau entre-aidants
Réseau FADOQ
Rêvez la vie
ROQP: Regroupement des onco-psychologues du Québec
RQFE: Réseau québécois des femmes en environnement
Société de leucémie et lymphome du Canada
Société de soins palliatifs à domicile du Grand Montréal

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Appendix 3

CPC financial partners and oncology products that have been rejected or not yet evaluated by INESSS

Legend

	Period preceding the notice of compliance from Health Canada
2008.04	Date of Health Canada notice of compliance (year.month)
X (VT)	Refused for efficacy reasons (therapeutic value)
X (EC)	Refused for economic or pharmaco-economic reasons
US	Still under study, no result yet
A :	Approval
A (C\$):	Approval conditional to an agreement with the manufacturer to share financial risks
1st, 2nd:	First-, second-line therapy
LLA:	Acute lymphoblastic leukemia
NHL:	Non-Hodgkin's lymphoma
GBM:	Glioblastoma multiforme
CLL:	Chronic lymphocytic leukemia
MRC:	Metastatic renal cell carcinoma

Partners 2011-2012	Products (Indication)	2006	2007	2008.02	2008.10	2009.06	2009.10	2010.02	2010.06	2010.10	2011.02	2011.06	2011.10	2011.11	2012.02
Amgen Canada	Vectibix (colorectal)			2008.04	X (VT)										X (EC)
AstraZeneca	Iressa (lung)									X (EC)	US		X (EC)	A (C\$)	
	Caprelsa (thyroid)														2012.02
	Faslodex (breast)				X (EC)										
Bristol Myers-Squibb	Erbix (colorectal)					X (EC)									X (EC)
	Sprycel (ALL)			X (EC)											
Boehringer-Ingelheim	afatinib														
	nintedanid														
Eli Lilly Canada	Alimta (lung)		X (VT)			X (EC)	X (EC)	X (EC)					X (EC)	A (C\$)	

Partners 2011-2012	Products (indication)	2006	2007	2008.02	2008.10	2009.06	2009.10	2010.02	2010.06	2010.10	2011.02	2011.06	2011.10	2011.11	2012.02
GlaxoSmithKline	Tykerb (breast HER2+)				2009.05					X (VT)/2nd					A/1st
	Bexxar (NHL)	X (VT)													
Hoffman-LaRoche	Avastin (GBM)									X (VT)		X (VT)			X (VT)
	Avastin (breast)						X (VT)						US		
	Avastin (lung)							X (VT)	X (VT)						
	Herceptin (stomach)												US		X (EC)
	Rituxan (CLL)												US/2nd		A/2nd
	Tarceva (lung)												X (EC)		
	Zelboraf (melanoma)														2012.02
Janssen	Zytiga (prostate)											2011.07			X (EC)
Lundbeck	Treanda (NHL)														
	Treanda (CLL)														
Merck	Zolinza (NHL)					2009.06									
	dalotuzumab														
	ridaforolimus														
Novartis	Afinitor (kidney)						2009.12			X (VT)			X (EC)	A (C\$)/2nd	
	Zometa (MRC)								X (VT)						
Pfizer	Sutent (pancreas)														
	Torisel (kidney)		2007.12		X (EC)										A
Sanofi-Aventis	Jevtana (prostate)											2011.06			X (VT)
Total refused / Under study		1	1	1	3	2	2	2	2	5	0/1	1	4/3	0	6